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ABSTRACT

This paper describes a model for the involvement of primary health care personnel in the identification and treatment of developmental disabilities as a part of early childhood intervention programs. The integrated multidisciplinary model is divided into four stages. During the first stage an assignment of prenatal, perinatal, and postnatal risk is made. The second stage consists of rapid screening, including administration of the Denver Developmental Screening Test, the Infant Rapid Screen, or other screening instruments. The third stage consists of referral for a comprehensive interdisciplinary developmental assessment of those children identified as being at risk. Stage four, consisting of assumption of medical responsibility, includes the role of pediatricians or other primary health care providers to provide case management and contribute to solving the multiple problems of these youngsters. The last stage would include follow through and coordination of subspecialty and special medical services, routine medical care, and participation in the comprehensive treatment and remediation plan designed by all the professionals who are involved with the child and family. (RJC)

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# A Four Stage Approach To Early Childhood Intervention

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# A FOUR STAGE APPROACH TO EARLY CHILDHOOD INTERVENTION

The Congress of the United States recently established a national discretionary program for early intervention for handicapped and potentially at risk infants and toddlers.[1] Prior to this time, only a handful of states had a systematic Early Childhood Intervention Program (E.C.I.).

As primary health care personnel are frequently the very first and only ones to see and follow these children in the first year and one-half of life, it became quite apparent that there would be a need to involve them in an unprecedented manner. Furthermore, problems would evolve on how to link the medical and public health community with other professionals in the E.C.I. community.

This paper will explore a four stage model which will offer a practical approach to some of these problems. Many professionals ask: "Does early childhood intervention really work?" Results from the states where ECI programs already exist are gratifying. A recent study by the Department of Education of the state of Colorado[2] showed that when 1,300 children were identified as having handicaps by their physicians early on and were given appropriate remediation, one-third began school without any additional help, one-third with minimal help, and only one-third required full time

special education services. On the other hand, almost all children who were not identified early and were not given early remediation required extensive special education services.

In Texas last year one-fourth of the children enrolled in the state ECI programs were graduated into regular education classes.[3] In addition, early identification helps reduce stress in family members by offering counseling and other services. In a group of 300 parents surveyed, 89% indicated that ECI helped reduce family stress.[4] There is no question that such support is frequently the difference as to whether a family unit remains functional or becomes disordered and eventually unstable.

Shonkoff[5] recently evaluated thirty one selected studies to assess the effect of early intervention services on disabled children younger than three. He concluded, "Results indicate that early intervention is effective in promoting developmental progress in infants and toddlers with biologically based disabilities."

Brazleton[6] states that even a mildly impaired infant may present disorganized behavior that makes him appear more impaired than he really is. "The timing of intervention is not only critical in addressing the strengths of assets with which the infant and parents can overcome deficits, but also

is significant in reinforcing a positive self image in that baby from the first and in adding motivation to optimal recovery. Otherwise, expectations for failure are built in very early and blankets everything the child and family attempt to do."

Without doubt, early identification of these youngsters can do a great deal for the physical, mental and educational well-being for them and their families. An integrated multidisciplinary model for developmental disabilities as a part of ECI can be thought of as occurring in four stages.

Insert Table 1 Here

STAGE I: Assignment of risk, STAGE II, rapid screening, STAGE III, referral for a comprehensive interdisciplinary workup, STAGE IV, MEDICAL RESPONSIBILITY, to include 1. follow through and coordination of subspecialty and special medical services. 2. routine medical care, and 3. participation in the comprehensive treatment and remediation plan designed by all the professionals who are involved with the child and family. The level of participation to be determined by the interest and skill level of the primary health care provider.

The first two stages should be of high priority to practicing pediatricians or any of the primary health care professionals who see infants and toddlers. But does this occur? All too often in the United States, it does not! When one asks the question: "Do pediatricians follow children with various developmental diagnostic tools?" the answer in the the past has been disappointing. One survey in the Northeast indicated that only 15% of all pediatricians surveyed followed children in this manner even though 97% stated that all children should be studied in this way.[7] Even more disappointing was Nelson's[8] study in the Southeast that indicated that even when dealing with babies of higher risk, only 39% of pediatricians and 29% of family practitioners[4] actually performed developmental assessment during office visits. This study also indicated that, while the diagnosis of cerebral palsy and developmental delay can be readily made before age one, referral for therapeutic intervention frequently did not occur until two years of age or later. To take this a step further, 136 infants from an Neonatal Intensive Care Unit (N.I.C.U.) were recently followed. Thirty five of these infants were identified as having a major handicapping condition such as blindness, deafness, cerebral palsy or developmental delays. All of these had a source of primary health care and visited their primary

health care provider on the average of four times a year. However, 75% had not been recognized as having a significant developmental disability. Of the 25% identified by their primary care provider, 83% had not been referred for treatment or remediation early on. This author[9] concluded that primary health care in the communities involved was not as effective in early diagnosis of developmental disabilities as desirable.

However, it is hoped that programs developed by the United States government and the American Academy of Pediatrics aimed at physician education and awareness in this area will help to solve this dilemma in the near future.

In the light of such information, the need for formal office developmental assessment is essential.

There are 3,760,000 live births a year in just the United States alone.[10] While I would like to see all children screened developmentally, in reality this does not occur. Some blame lack of time, cost, or lack of personnel. But, for whatever reason, frequently it does not occur. Who, then, should be assessed and screened?

We can at least make sure that those children who are at greatest risk are appropriately identified. By focusing on this population in the United States, one no longer need

screen 3,760,000 newborns a year, but assess those at risk. This stage, assessment of risk, can be thought of as consisting of prenatal, perinatal and postnatal risk.

Prenatal Risk Factors

1. lack of prenatal care
2. mother over 35 or under 16
3. maternal history of mental retardation
4. drug or alcohol abuse
5. parental history of mental illness
6. family history of child abuse or neglect
7. family history of deafness
8. chaotic home environment
9. maternal history of AIDS
10. major sociopathy

Meisel[11] suggests that all lower socioeconomic subjects and all subjects who have parental education below the twelfth grade are at risk. I do not feel that this, in itself, connotates risk unless these cause the above or some of the subsequent risk factors.

Perinatal and Neonatal Risk Factors

1. birth weight < 2,500 and especially < 1,500 Gms.
2. Apgar Score of 4 at five minutes with continued signs of depression

3. Bilirubin > 17, especially when associated with Rh or ABO incompatibility. (jaundice)
4. obvious genetic or congenital malformations
5. infections such as sepsis or meningitis
6. neonatal seizures
7. maternal disease - diabetes, infection or ingestion of medication for seizure, etc.
8. metabolic abnormalities - low sugar, calcium, PKU, hypothyroid, etc.
9. IVH - especially grade 3 or 4
10. Respiratory Distress Syndrome (R.D.S.)
11. infant in hospital after mother leaves

Postnatal Risk Factors

1. head trauma
2. near drowning victims
3. seizures < two years
4. children diagnosed or treated for tumors or leukemia
5. child abuse or failure to thrive
6. AIDS

The above groups represent a very large population. To fully evaluate each child from this population would probably be beyond reasonable and acceptable cost, staffing, capability and time contraints. Therefore, the second stage consists of utilizing one of several prescreening or screening instruments.

Although recently criticized by Meisels[12] for under-identification, the Denver Developmental Screening Test (DDST)[13] has long been the mainstay of primary health care developmental testing, and is the most widely used and standardized test on an international basis. It is designed to screen children 0 through 6 years old to see if they are delayed in development. Its authors claim that it effectively identifies over 85% of preschool children who are developmentally delayed. The DDST was developed for use by persons with no previous training in psychological testing and was designed to be easy to administer and interpret. It is not meant to be an intelligence test, but to simply and effectively serve as a signal to the examiner that a referral for a more detailed evaluation is needed.

Although easy to administer, the full Denver takes fifteen to twenty minutes and thus, may be too time consuming when large populations, lack of personnel, large clinical practices or time lines come into play. Because of this, two prescreening tests initially evolved. One was the short form Denver,[14] and the other, the Parental Developmental Questionnaire (P.D.Q.)[15], a parental questionnaire. Recently, these authors published the P.D.Q.-R.[16] key item DDST,[17] and a revised DDST.[18] According to the authors, 81% of children who fail a DDST and 61% who are questionable will manifest school problems or an IQ below 80 at three years or later.

A more recently developed screening test is the Infant Rapid Screen (IRS).[19] It was developed as a prototype for the Texas High Risk Infant Registry Task Force. In utilizing the IRS, responses to each item may be elicited by history, observation, or physical examination. Developmental screening sheets are utilized at two, four, six, nine, twelve and fifteen months of age. For the most part, they correspond to when these children are usually seen for immunization. A one-month visit sheet was later added. This was simply to make sure that infants could see, hear, move all extremities, and have certain basal reflexes. Each testing interval is divided into social adaptive, fine motor, language-visual, gross motor, and reflexes. Yes or no is simply checked for each item. Two misses on a given testing interval followed by two misses on any subsequent interval is indicative of risk requiring full assessment. Adjustments for prematurity are not made on the IRS as they are on other tests. The maximum mean time to administer the IRS was the six month screen, which took one minute and twenty nine seconds. The remainder of the monthly screens took approximately one minute.

The IRS takes less than two minutes to administer and seems to identify more youngsters as being at risk than the full DDST, particularly in the rubric consisting of children

with various conditions that would make them more susceptible to developmental delay and handicapping conditions. In comparative studies of 228 children not at risk for developmental delays, six failed the IRS and five, the full DDST. In comparative studies of 81 children who had conditions which made them at risk for developmental delays and disabilities, 23 failed the IRS and 12 failed the full DDST. Six were questionable on the full DDST.

Insert Table 2 Here

We are currently in the process of developing the Toddler Rapid Screen (TRS) with test periods at 18 months, 2 years, and 2 1/2 years of age. Field testing on this instrument will begin in early 1990. The Texas Preschool Screening Inventory (TPSI),[20] which had previously been developed by our group to indicate potential learning problems in 4-6 year-olds before they matriculate in school, will be scaled down to cover the 3 year-old group.

Some other screening devices recently in the literature are the Clinical Language and Auditory Milestone Scale (CLAMS)[21] and Early Language Milestone Scale (ELMS)[22] for language. The Early Language Milestone Scale is not a

particularly good test. In recent clinical trials involving large numbers of children from several centers Tomblin[23] noted that seventy-five percent of the subjects identified to be at risk on an ELMs screen actually were normal when comprehensive speech and language testing was performed. This experience has also been noted by others. The Clinical Language Milestone Scale is a continuum of expressive and receptive skills ages 0-36 months that is ascertained by parental questionnaire. Lastly, the Home Screening Questionnaire (HSQ)[24] is a short vesion of the Home Observation for Measurement of Environment (HOME) developed by Coons and associates. It is meant to identify those children who might be at risk for developmental delay and disabilities because of their environment. It was standardized only on lower socio-economic populations and, therefore, may not identify environmental risk in middle upperclass children. Further, the sample of black children was only six percent in one population studied and 8% in the other.

All screening tests should be restandardized on any population in which they are being used for the first time. Indeed, they should be brief, referenced to a norm, inexpensive, standardized in administration, objectively

scored, cover all areas of performance, developmental in content, reliable and valid.[25] Screening instruments are not entirely sufficient as predictors when used by themselves or as a singular spot test without followup. They are only optimal when used with surveillance over a continuum of time by experienced clinicians, educators, and observers.[26]

Indeed, screening devices that suffice for very young infants and toddlers such as the DDST or IRS will not pick up some of the subtle linguistic, perceptual, memory or cognitive deficits that may hinder higher learning and lead to learning disabilities and other related problems in the preschool and elementary school child.

Therefore, one must continue surveillance of high risk children on a second plane utilizing tests such as the Texas PreSchool Inventory (TPSI)[27] or others prior to the childrens' matriculation in school to further delineate these potentially handicapping conditions which are not frequently measured adequately by tests in very early infancy and childhood.

The Third Stage consists of referral for a comprehensive interdisciplinary developmental assessment of those youngsters identified as being at risk. It behooves physicians and other health professionals who care for children to know what facilities are available in their

practice area and have good communication with them. They should participate as part of his multidisciplinary effort either in their private office or at an appropriate center. This should include a detailed medical history (to include prenatal, birth-neonatal, developmental, family-environmental and past-medical), physical and neurologic examination, necessary laboratory and other ancillary medical tests and findings. Non-Pediatricians, depending on training or interest, might wish to involve a consulting pediatrician at this point.

Assessment at such centers should include comprehensive language, speech, sensory, psychosocial, self help skills, cognitive and motor evaluations. Sociologic interaction within the family should be explored. In the United States Early Childhood Intervention (ECI) system, all this ideally will result in a treatment plan called the Individual Family Service Plan or IFSP.

Most of these youngsters also have various medical problems. Frequently, the primary health care provider was the initial referral source and knows the family well. Therefore, he should become an integral part of that plan.

Stage Four is that of medical responsibility. It becomes the role of pediatricians or other primary health care providers role to help case manage and contribute to solving

the varied problems of these youngsters. In this capacity the physician has responsibility for follow through and coordination of the frequently required subspecialty and special medical services. This can help maximize care, prevent duplication of services and unnecessary cost to the family and prevent unnecessary procedures and trauma to the child. The primary health care provider can be the glue and the hand that helps all hands to know what they are doing.

While exploring the complicated, one must not forget the common preventative measures of good routine pediatric care in both sickness and health. This, too, has its important place in the fourth category.

How much pediatrician or other health care provider becomes involved in helping to plan, implement or be a participant in the previously discussed IFSP will depend greatly upon their individual knowledge, expertise and interest.

New legislation in the Unites States will help create new facilities and expand existent facilities for extensive evaluation and remediation for handicapped infants and toddlers. It is hoped that health care and other professionals involved with young children will work in a partnership in the progression of care for the advancement of the quality of life for these children andtheir families, thus, helping them to maximize their potential.

While the use of this 4 stage plan may be limited to highly structured Early Childhood Intervention (ECI) and medical systems, it may also be useful in a modified form where there are limited resources by training ancillary paramedical and non-professional support personnel.

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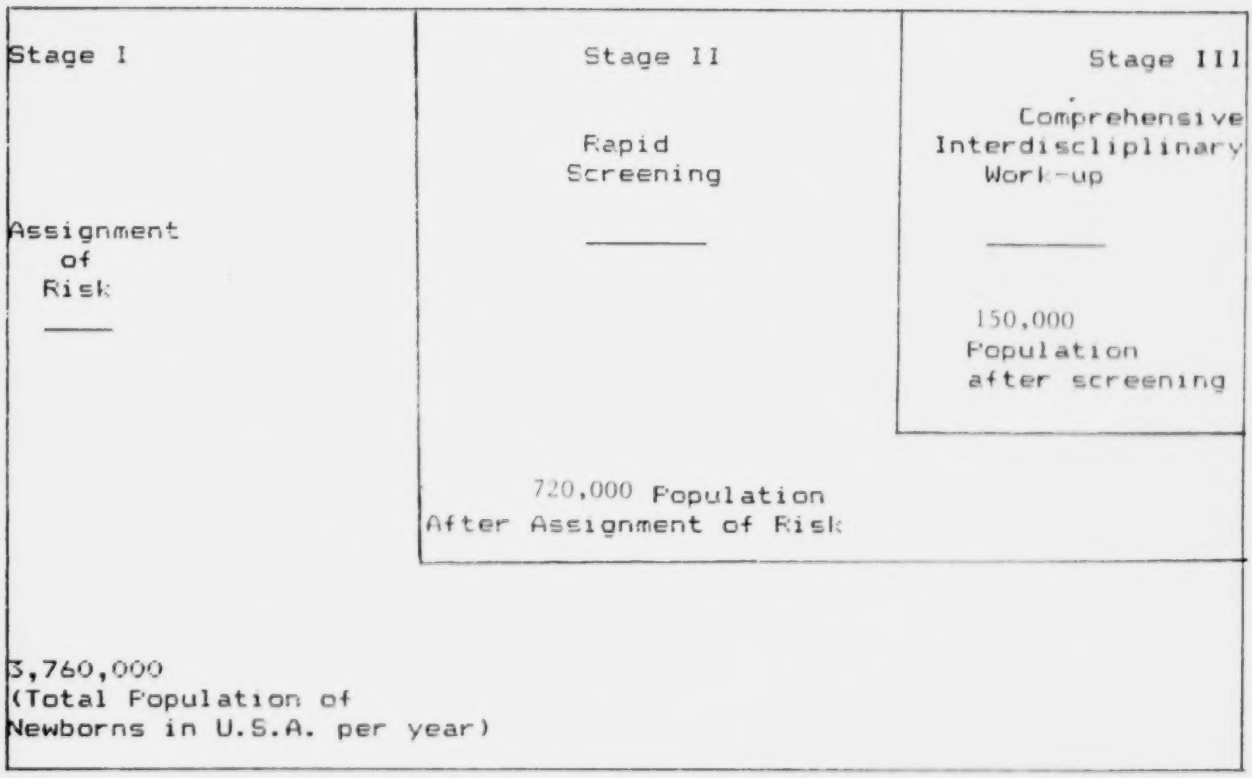
TABLE 1




STAGE IV - MEDICAL RESPONSIBILITY

TABLE 2

INFANT RAPID SCREEN (IRS)

| | |
|---|---|
| Total Subjects | 380 |
| High Risk | 101 |
| Low SES | 58 |
| Male | 204 |
| Female | 176 |
| White | 263 |
| Black | 62 |
| Mexican American | 28 |
| Asian American | 27 |

CHILDREN WITHOUT RISK FACTORS

| | |
|---|---|
| Total | 279 |
| Passed IRS | 232 |
| Passed DDST | 233 |
| Failed IRS | 6 |
| Failed DDST | 5 |
| Questionable DDST | 0 |
| Testing still in progress-comparative data available later | 41 |
| Total taking IRS and DDST | 233 |

CHILDREN WITH RISK FACTORS

| | |
|---|---|
| Total | 101 |
| Passed IRS | 58 |
| Passed DDST | 63 |
| Failed IRS | 23 |
| Failed DDST | 12 |
| Questionable DDST | 6 |
| Testing still in progress-comparative data available later | 20 |
| Total taking IRS and DDST | 81 |

No subjects passed an IRS and subsequently failed a DDST

MEAN TIME TO ADMINISTER

| | |
|---|---|
| 2 mos. | 52 seconds |
| 4 mos. | 51 seconds |
| 6 mos. | one minute & 29 seconds |
| 9 mos. | one minute & 05 seconds |
| 12 mos. | 58 seconds |
| 15 mos. | one minute & 12 seconds |